

IF Statement on Strengthening Rehabilitation in Health Systems for persons with Spina Bifida and Hydrocephalus

Introduction

The International Federation for Spina Bifida and Hydrocephalus (IF) is a precursor with its long-time focus on rehabilitation. Almost thirty years ago, IF contacted the World Health Organisation and proposed to work together for producing a guide for mid-level rehabilitation workers ⁽¹⁾, to be used for children with Spina Bifida and Hydrocephalus (SBH).

Years later, IF still holds the topic high in its agenda. Its previous positions focused notably on the need for the access to multidisciplinary care for persons with SBH ⁽²⁾ or its response to the consultation launched by the United Nations Special Rapporteur on the Rights of Persons ⁽³⁾ with Disabilities. Two reports have also been published on the right to health and the reality of persons with SBH ⁽⁴⁾ and on the best practices on ageing with SBH ⁽⁵⁾. From these documents, IF mainly highlighted the fact that persons with SBH need a care from a broad variety of different services and medical specialists, adapted to their specific needs, allowing them to live an independent and healthy life.

Earlier this year, the 76th World Health Assembly Resolution on strengthening rehabilitation in health systems has been adopted ⁽⁶⁾. According to a report made by the Director General ⁽⁷⁾, this resolution was made due to the context of increasing unmet needs for rehabilitation and that, in many countries, more than 50% of persons have no access to a rehabilitation services. In addition, the sustainable development goal number three has been mentioned, which plainly states that rehabilitation services are key for ensuring healthy lives and promoting well-being for all ages. Besides, the resolution urges to raise awareness for a national commitment for rehabilitation, to strengthen financial mechanism, to expand rehabilitation to all levels of health, to develop a strong multidisciplinary rehabilitation, to enhance a health information system while ensuring high quality rehabilitation research.

This statement outlines (1) what rehabilitation is; (2) why strengthening rehabilitation for persons with SBH is necessary; (3) list of actions at global level on how to strengthen rehabilitation in health systems for persons with SBH; (4) barriers for making the rehabilitation a reality for all persons with SBH; and (5) IF's recommendations on strengthening rehabilitation for SBH in health systems.

Rehabilitation

The World Health Assembly Resolution on strengthening rehabilitation in health systems originated its source from a World Health Organisation report ⁽⁸⁾. This report explains what rehabilitation is: *it is a set of interventions needed when a person is expecting limitations in everyday physical, mental and social functioning due to ageing, or a health condition, including noncommunicable diseases or disorders, injuries or trauma.*

Besides, the 76th World Health Assembly Resolution on strengthening rehabilitation in health systems ⁽⁹⁾ stated that the benefits of having an affordable rehabilitation service can significantly reduce the health care costs and the burden of care providers. At the same time, it increases our quality of life, , raises our well-being and health, delays the need for long-term care, and empowers us to achieve our full potential and participation in society.

As explained in the guide for mid-level rehabilitation workers made by the World Health Organisation in collaboration with IF in 1996 ⁽¹⁰⁾, rehabilitation is a key solution for ensuring we have an independent and healthy life from childhood to ageing. Indeed, as stated in a previous IF statement on multidisciplinary care ⁽¹¹⁾ and in the IF multidisciplinary care-conference book ⁽¹²⁾, persons with SBH and their families need a wide range of different services and medical specialists while benefitting from a coordinated support of these services in one place. This statement highlighted the fact that a lack of coordination leads to long distance traveling for meeting different specialists who, in addition, can be unaware of different needs we have. Rehabilitation can ensure that we follow a coordinated service which encompasses all of our needs with healthcare professionals who acknowledges us as a whole and not focusing on solely on our symptoms. Rehabilitations for persons with SBH also helps to decrease preventable comorbidities and invasive procedures like surgeries at the hospital.

Why strengthening rehabilitation for persons with SBH?

As described in the IF statement for a global action to reduce the prevalence of neural tube defects ⁽¹³⁾, Spina Bifida is a result of the neural tube not closing correctly, resulting in damage to the spinal cord and nerves. It can be accompanied with Hydrocephalus, a condition in which cerebrospinal fluid accumulates in the brain. Both are complex health conditions that lead to disability and affects mobility, bladder control and cognitive functions. This is why IF considers that health is an enabler of inclusion ⁽¹⁴⁾ and this can be achieved through a set of multidisciplinary services. Without it, we face pain, loss of mobility or difficult recoveries from surgical procedures.

We require an early diagnosis and access to medical care since our condition can evolve throughout our life. This implies access to life-long persons-centred multidisciplinary care. Rehabilitation can support us to achieve our human rights, enjoy societal inclusion and reach our full potential. By being able to self-manage our health and having an independent life, we can increase our life expectancy ⁽¹⁵⁾.

Strengthening rehabilitation for us means providing proper training to the health care professionals in order to provide us with adequate care. The main issues faced by us is the dispersion of healthcare services and the lack of competent professional healthcare. It takes us lots of time and energy to go from one service to another without any coordination from the healthcare services. Furthermore, healthcare specialists tend to focus on the disease to be curated instead of considering us as a whole, which can be followed with discrimination and stigmatisation. An article ⁽¹⁶⁾ enlightens on the deficient integration of rehabilitation in healthcare services and the negative attitudes of caregivers and health-care providers. Despite the vital need of having access to healthcare services, this necessity adds a burden on our mental health as we have to deal with misconceptions towards us, without mentioning the fact that an uncoordinated rehabilitation service means we cannot know if the practitioner we meet will provide the same comprehensive care as the previous one. If it is not the case, we may have to explain again our specific needs.

Socially discriminating challenges faced by our caretakers and us include parents being advised to put their newly diagnosed child with SBH in institutions, or other segregated settings, to older persons with SBH not receiving support for their changing needs, which could result in unemployment and

homelessness. Amongst the persons that face the lack of accessible support, healthcare services or access to education, a good portion of us have a higher prevalence of SBH ⁽¹⁷⁾. Rehabilitation is actually needed at different stages of life. As it was expressed in our previous IF statement on multidisciplinary care for Spina and Hydrocephalus ⁽¹⁸⁾, rehabilitation and multidisciplinary services are often dedicated to children. It leaves a little room for an effective transition between childhood to adulthood and then from being an active adult to an older individual with SBH ⁽¹⁹⁾.

On that account, rehabilitation has multiples benefits ⁽²⁰⁾. Reducing the impact of health conditions, especially for persons with SBH, preventing eventual complications, minimizing the hospitalisation costs while ensuring we can get an education, secure employment, or simply stay autonomously at home. This is an investment followed with cost benefits. Several initiatives have been implemented to provide services for us, especially those with SBH.

List of actions at global level on how to strengthen rehabilitation in health systems for persons with SBH

The World Health Organisation published different guides and plans: the guide for mid-level rehabilitation workers ⁽²¹⁾ and the Rehabilitation 2030. ⁽²²⁾ It is followed by two guidelines: *Rehabilitation in health systems: guide for action* ⁽²³⁾ and *Rehabilitation Competency Framework* ⁽²⁴⁾. All of them offer a framework for strengthening rehabilitation in health care services. Then, the WHO adopted the 76th World Health Assembly Resolution on strengthening rehabilitation in health systems ⁽²⁵⁾. It urges the WHO Member States to raise awareness and build national commitment for rehabilitation, to strengthen financial mechanisms, and to expand rehabilitation to all levels of health while ensuring availability. Moreover, enhancing the quality and timeliness of rehabilitation services, to develop strong multidisciplinary rehabilitation skills, to promote the development of initial and continuous training of professional and staff, to recognize different types of rehabilitation needs, to collect data disaggregation for a relevant health information systems related to rehabilitation, and promote high quality rehabilitation research.

Rehabilitation contributes to the respect of human rights related to the needs of persons with disabilities. These rights are mentioned in the United Nations Convention on the Rights of Persons with Disabilities and more specifically in Articles 19, 25 and 26 ⁽²⁶⁾. The third paragraph of Article 23 from the Convention on the Rights of the Child ⁽²⁷⁾ mentions the right for children with disabilities to have an effective access to rehabilitation services. The fourth paragraph of Article 23 of the Convention on the Rights of the Child ⁽²⁸⁾ expresses the necessity to disseminate and share information on rehabilitation methods.

During the World Spina Bifida and Hydrocephalus Day 2023 ⁽²⁹⁾, IF members from Africa, Asia-Pacific and Europe shared their good practices for an accessible healthcare. They stressed the importance of rehabilitation for us through an accessible healthcare service while collaborating with other associations and networking with international organisations. To keep a close tie with the public authorities, it is a worthwhile endeavour to be granted a consultative status for questions related to the relevant area of work that has an impact on our lives. Some IF members shared their experience by using a peer-to-peer approach for tackling any disability challenge. Creating manuals for public authorities to make their decisions more disability inclusive as part of the solution. In the same way, the EU has recently opened the EU accessible resource centre, which will help stakeholders work together for ensuring the accessibility of a given project.

Despite all of these positive actions and practices that enhance an inclusive rehabilitation service, we still face challenges for having full access to such services.

Barriers in ensuring access to rehabilitation for all

The main barriers that we face for having access to rehabilitation are inaccessible healthcare services⁽³⁰⁾, uncoordinated multidisciplinary care services, the lack of competent health care professionals, difficulties keeping a long-term relationship with practitioners as they regularly move from one service to another. Despite their being sufficient childcare services for children with SBH, similar attention is not given for facilitating the transition from childhood to adulthood in terms of healthcare support⁽³¹⁾. Rehabilitation and healthcare services are rarely accessible for us in remote regions. In addition to these barriers, we regularly face negative stigma from healthcare professionals⁽³²⁾. We have a rare and complex condition which requires immediate specialised healthcare interventions, as well as lifelong support through integrated multidisciplinary healthcare. Unfortunately, our needs are rarely met⁽³³⁾.

During the WSBHD23, the speakers from different regions also shared their concerns for an accessible healthcare. There are different perspectives on accessibility in various places around the world. In Europe, accessible healthcare services are not complete as there is a lack of assistive products⁽³⁴⁾, which is part of the rehabilitation requirements. In order to propose an inclusive healthcare service, it is necessary to urgently gather data for anticipating our needs⁽³⁵⁾. In Africa, accessible specialised healthcare services are not common, as there are limited specialised healthcare services and facilities to provide treatment and support⁽³⁶⁾. In addition, they emphasised on the lack of trained staff in the healthcare sector, which makes it less accessible for us. In Asia and Pacific, it has been said that the lack of universal healthcare coverage⁽³⁷⁾ reduces the chance to improve our health, and it was mentioned that financial barriers make the care very expensive since there is no universal funding scheme⁽³⁸⁾. There is also a lack of disability-related capacity within their ministries of health, which reduces the chances of having an accessible healthcare service⁽³⁹⁾. The WSBHD23 enlightened the importance of an accessible rehabilitation service for us, the need for full access to multidisciplinary care, and to raise awareness to tackle stigmatisation and discrimination. It has also been mentioned that there is a necessity to acquire universal social protection, and to strengthen healthcare systems.

Given the urgent need for strengthening rehabilitation in health systems, the 76th World Health Assembly resolution made clear recommendations to the World Health Organisation Member States in this regard. By stressing out the benefits of having an independent life at every stage of life, to decrease the hospitalisation cost, to improve the education level and improve the employment rate of persons with specific needs, it will incite the Member States to follow its recommendations in order to accelerate the actions for a strong rehabilitation in their healthcare systems.

Many countries do not collect relevant data on the access of persons with disabilities in their healthcare systems, which obstructs the objective of implementing a targeted and accessible healthcare service for them. There is little data on disability that measures the effect of different environmental factors⁽⁴⁰⁾.

These barriers are an infringement to the core principle of the UNCRPD Article 25 on the attainment of the highest standard of health without discrimination on the basis of disability. Persons with SBH have a particular need of having an accessible rehabilitation through a coordinated multidisciplinary care service. With the fact that integrated services facilitate early access to care and information, an efficient rehabilitation service empowers them. Not only in the medical way, but also in our lives as a whole. From the well-being of removing the stress, to not meeting our needs which damages our mental health, to the perspective of keeping an independent life while ageing, rehabilitation is a key solution for guarantying needs.

In order to ensure Accessibility for All, IF hereby presents the following recommendations for strengthening rehabilitation for SBH in health systems to policy makers, healthcare professionals and organisations:

Recommendations:

- IF recommends that research into the development of integrated rehabilitation for SBH in health systems be strengthened and that policy makers, international organisations and other relevant stakeholders' incentives research through actions such as increased availability of funds and resources;
- IF recommends that the crucial role of SBH associations in providing guidance and support to persons with SBH and their families be recognised and that the SBH community be involved in the development of rehabilitation for SBH in health systems to ensure inclusion and person centred care;
- IF recommends that policy makers, international organisations and other relevant stakeholders take an integrated multidisciplinary approach to developing healthcare services in low-income countries;
- IF recommends that policy makers on the national and regional level instigate the development of national guidelines and policies for the development of rehabilitation for SBH in health systems in order to tackle regional inequalities in access to care as per article 25(c) of the UNCRPD;
- IF extends to healthcare professionals and healthcare professional organisations and invitation to join IF in calling for integrated rehabilitation for SBH in health systems;
- IF reminds the importance of implementing a raising awareness strategy for accessible rehabilitation services to policy makers, international organisations and their funding programmes.

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ABOUT IF

The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing people with Spina Bifida and Hydrocephalus (SBH) and their families worldwide. IF has country members in Africa, Americas, Asia-Pacific, and Europe with unique and expert knowledge on SBH. The mission of IF is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of Neural Tube Defects (NTDs) through improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

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